

Palliative Care: are we all speaking the same language?

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Palliative care...

...are we all speaking the same language?





Palliative care has an identity problem.

(New England Journal of Medicine)

Some popular beliefs

Palliative care only means you're dying.

Palliative care is part of a conspiracy of silence.

Additionally...

70% of 800 adults surveyed in the US, said they were "not at all knowledgable" about palliative care



The World Health Organisation (WHO) definition explains that palliative care:

"...is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Palliative care provides patients:

"...with relief from the symptoms, pain and stress of a serious illness – whatever the diagnosis...Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment."



Yet...

The popular belief is often that palliative care is only associated with death and dying. While palliative care certainly plays a critically important role at the end of life, good palliative care is also very relevant to many earlier stages of a disease, often a considerable time before death is approaching.



In addition, there seems to be confusion among healthcare professionals too.

"[Palliative care is]
comfort care during
one's last few weeks
of life to allow patients
to pass in comfort and
dignity." *

"Palliative care is helping families to give them comfort and options for what to do at their loved one's end of life." *

^{*} US National Pain Report, National Pain Foundation

Early palliative care for the whole cancer journey...



Medications to ease pain and for symptom control

Help to cope with fatigue

Psychological support to help cope with anxiety and depression

Spiritual and existential counseling



Neuro oncology and palliative care: a challenging interface

Lin E, Rosenthal MA, Le BH, Eastman P, *Neuro-Oncology and Palliative Care: a Challenging Interface*, Neuro Oncol, Sep 2012 (Suppl4): iv3-iv7|DOI 10.1093/neuron/nos209

"Palliative care teams bring complementary expertise in symptom management, communication skills and practical physical and psychosocial support, both within and outside the hospital environment... it follows that palliative care should and must become an integrated standard part of best practice neuro-oncologic care..."



Demistify... Clarify...

Consistent communication is paramount!

An open and frank dialogue is needed with all stakeholders: patients, caregivers, families, healthcare providers, the media, general public, key opinion leaders and politicians.





Involve patient organisations in the process.



First World Summit of Brain Tumour Patient Advocates Lafayette, California, November 2013



- The ESMO Designated Centres of Integrated Oncology and Palliative
 Care accreditation programme was initiated in 2003.
- Cancer centres can receive special recognition for achieving a high standard of integration of medical oncology and palliative care.
- Currently, there are 175 centres accredited in 37 countries
- Size of institution is not important what really matters to be eligible for this scheme is the quality and extent of palliative care service integration.

ESMO Designated Centers – Geographical breakdown

Country	No. of centres	Country	No. of centres
Italy	39	Georgia	2
Germany	23	Singapore	2
Spain	15	Slovenia	2
The Netherlands	11	Turkey	2
Belgium	10	Argentina	1
United Kingdom	7	Brazil	1
France	7	Bulgaria	1
India	5	Colombia	1
Australia	4	Czech Rep.	1
Switzerland	4	Hungary	1
USA	4	Korea	1
Canada	4	Malaysia	1
Egypt	4	Norway	1
Hong Kong	3	Poland	1
Austria	3	Romania	1
Ireland	3	Russia	1
Israel	3	Sultanate Oman	1
Greece	2	Peru	1
Portugal	2	Total	175



Programme objectives

- Promote the integration of palliative care services into the existing national cancer care guidelines
- Encourage palliative care education and training for medical oncologists as well as other healthcare professionals
- Expand the cooperation between ESMO and other existing professional medical associations and organisations worldwide in supporting and sustaining palliative care development





The Oliver family with Colin (7 Aug 1979 – 27 Aug 2011)



Palliative Care...

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Thank you for listening



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Some parts of this presentation were taken from Kathy Oliver's article entitled *Demystifying Palliative Care* for the European Association of Neuro Oncology (EANO) online magazine, Issue 3/2014. See http://www.kup.at/kup/pdf/12441.pdf